DATE 1/22/13
HB Senior (Mg Term Care

MR Madame Chairman and members of the committee:

My name is Becky Cottrell. I live in Helena. I am here today representing my son Chase Hotchkiss. He is 30 years-old and lives independently in Missoula. Chase has cerebral palsy and requires personal caregivers four times a day. (1456 visits a year). This is coordinated through Home and Community Based Services and home health providers, who I am forever grateful. If not for them, I wouldn't be a Helena business owner, I would be a caregiver.

The last several years have been trying for Chase. He lost his father. He moved to Missoula to attend school and while living on campus, was exploited by a caregiver who over the course of 1 year, cohersed him out of over \$4,000. None of which has been repaid. He had emergency surgery to correct a crushed spinal cord which was causing him to lose feeling in his limbs. After months of recovery at a nursing home, we reinstated necessary services and he move back into his apartment. Chase is his own guardian. I maintain close communication with him, and case management.

On November 6<sup>th</sup> election eve, I received a call from Missoula police that Chase was at the emergency room and tried to commit suicide by cutting his throat, wrists and groin with a steak knife. He told the officer that he was tired of caregivers and living with a disability. Chase shielded me from discovering his loneliness and the on-going turmoil between him and certain caregivers. The details that start to unravel from here forward may be better addressed however with a legal panel. Chase spent the next 4 weeks at Providence mental health unit where he opened up for the first time about living with a disability. He begged the doctor and social worker not to discharge him. His case manager worked diligently pulling together new caregivers and preparing for his discharge. Without her help along with the new home health agency and Adult Protective Services, Chase would have gone into a nursing home.

I thank each of you for hearing our stories. Families in this room are in crisis. Agencies are understaffed; caregivers are underpaid and poorly trained. I am extremely grateful that Chase's suicide attempt failed....and that he's not the reason one more waiver slot opened up.

Shank you

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Today I'd like to challenge you to redefine disability and the image of who receives support from the DPHHS waiver program. I am 31, a mother of three, college educated and I used to be quite a successful business owner. But that changed when I was diagnosed with a rare auto-immune disease called neuromyelitis optica (NMO.) It's rare enough the medical community considers it an "orphan" with little to no support out there.

NMO has an attack phase similar to multiple sclerosis where it goes after the myelin covering the nerves, but in NMO it specifically targets the spinal cord and optic nerves.

Two years ago, after an extremely debilitating attack, I was left almost completely blind and paralyzed – completely wheelchair bound. Here I was, facing a terrifying diagnosis where research showed I'd be unlikely to live another 2 years. They said regaining sight would be a lottery draw and that I'd never feel my legs again. This point is where I first met the waiver team.

I recall thinking how ridiculous it was trying to be a good hostess when I couldn't tell if we were sitting in the dark or not. I'm sure I looked like quite a mess, trying to pick an outfit based on touch alone, heavily medicated, losing hair with the chemo treatment and bashing my power chair into everything. I was horribly depressed and reeling from the utter lack of control I felt over anything. None of that slowed the waiver team at all, they knew what they had available and immediately starting improving things.

I complained that I couldn't get to certain places in my home; they came in with a contractor and installed ramps. I complained that I couldn't get my power chair to the store; they came in and had someone look at modifications to my van. I complained that I didn't have any energy; they came in with modified personal care time to help with household duties.

Whether those were to be my last days, or just the first ones in a long road of chronic illness, didn't matter to anyone involved. Those simple things really changed the way I viewed my disease and my ability to process everything. As I regained sight and learned to control my body and balance even without feeling my legs, I always had my support team by my side to cheer me on or listen to me whine. Even with as far as I've come I know that at any minute it might all be taken — but I'm facing it with optimism this time around after seeing how much help and support is available.

Thank you,

Jennifer Bratt